NICE: A national quality system in Intensive Care for and by the professional group of intensivists

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In 1996 NICE (National Intensive Care Evaluation) was founded, on the initiative of an professional group of intensivists, to gain insight into and to improve the effectiveness and efficiency of Dutch intensive care units (ICUs). To reach this goal, an organisational and a technical infrastructure, among which a national database intensive care, were developed. In this chapter the motive, history, structure and activities of NICE are described.

3.1 Motive for an intensive care quality system
Last decades the increased use of technological equipment and highly specialised personnel in intensive care (IC) improved the chance of survival of critically ill patients. In consequence, however, intensive care has become a very expensive treatment [1]. In the EURICUS-I study median costs of 25 European intensive care units (ICU) stand at € 692 per patient per day, varying between € 318 and € 2118 per patient per day (1996-price level) [2]. In 1992, research of the institute of Medical Technology Assessment showed mean costs per Dutch ICU varying between € 483 and € 1387 per patient per day [3]. The reimbursement of intensive care does not match to the real costs of intensive care treatment. Therefore, it is important to treat critically ill patients efficiently and to demonstrate the effectiveness of this expensive treatment. Next to economic motives, professional motives induced several initiatives to improve and rationalise intensive care.

Both nationally and internationally, several initiatives have been expanded to set up registries enabling quality assurance and quality improvement of intensive care. Examples can be found in Australia /New Zealand (ANZICS) [4], the USA (IMPACT) [5], United Kingdom (ICNARC) [6, 7], Italy (GiViTi) [8] and Belgium (SAPI). In Europe the EURICUS-study used samples to investigate the effectiveness and efficiency of European ICUs [9]. Some of these registries are intermittent (e.g. several months a year) and/or incomplete (not all patients admitted to the ICU during the registration period are recorded).

A quality system does not only contain one or more registers but also the analyses, feedback reports and a structure in which the professional group of intensivists discover and discuss the implications to improve intensive care treatment and organisation. In the Netherlands, the National Intensive Care Evaluation (NICE) foundation was established in 1996 to enable such a quality system for Dutch ICUs.

3.2 History of the NICE foundation
The NICE foundation is the follow up of the project “Dutch specifications for information systems in intensive care” supported by the Dutch government from 1993 till 1994. In this project intensivists and ICU-nurses from eleven hospitals, engineers from industrial parties, and scientists with a background of medical informatics were involved. They defined specifications for an information system in intensive care which is referred to as a Patient Data Management System (PDMS) [10]. One important specification was the definition of the minimal data set for a national database intensive care, which has to be collected from each admission to the ICU.

During 1996 eight participants (six intensivists who participated in the project “Dutch specifications for information systems in intensive care”, a representative of the CBO (the Dutch institute for Health Care improvement) and a scientist of the department of Medical Informatics in the Academic Medical Centre) defined the data items, and provided definitions and formats of the minimal data set.
NICE, the owner of the national database, was officially founded in September 1996. In 1997 a pilot study started in which ICUs of six hospitals ("Onze Lieve Vrouwe Gasthuis" (OLVG) in Amsterdam, Academic Medical Centre (AMC) in Amsterdam, University Hospital Utrecht (UMCU), Catharina Hospital in Eindhoven, Thorax center Ignatius in Breda and University Hospital Maastricht (AZM)) started to collect data according to the minimal data set specification. For three hospitals it took a full year (1997) to accommodate the PDMS to the minimal data set requirements and they started to deliver data at the end of 1997. The other three hospitals were not or just partly equipped with a PDMS. For that reason they decided to collect the minimal data set manually in a local database with or without filling in paper-based forms beforehand. Practice experience and the first results of data analyses gave rise to sharpening some definitions of the minimal data set and the data delivering procedures which were finalised during 1998. Since January 1999 participation to NICE became open for each interested Dutch ICU. In February 1999 the NICE foundation has trained four new participants which started the collection of the minimal data set from April 1999.

### 3.3 Quality assurance and quality improvement by a national database intensive care

The national database intensive care of NICE is an important tool to monitor the quality of Dutch ICUs in terms of effectiveness and efficiency. An idea about the effectiveness and efficiency can be obtained by comparing the outcome of an ICU to the expected outcome (based on case mix). Mortality constitutes one of the most important outcome measures of effectiveness in intensive care and is the starting point of NICE. Observed in-hospital mortality within an ICU population can be compared with the case mix adjusted expected mortality calculated by the prognostic scoring models. Discrepancy between observed and expected mortality within an ICU population and discrepancy between the ratio of observed and expected mortality of an ICU with the national ratio provide opportunities to discuss and to seek explanations for these differences. The care process is considered as a black box at this stage, because the input of (human) resources and its organisation is not yet considered. Until the minimal data set is extended with intervention and costs information, efficiency will be approximated by length of stay (see Figure 3.1). Explanations for the discrepancies in mortality and length of stay can be found in e.g. differences in treatment protocols or differences in the organisation of an ICU. From here, the professional group of intensivists gains insight into the quality of their ICUs and creates possibilities to improve it. NICE stimulates this process by providing quarterly standard reports and by organising annual meetings for the participating ICUs.

#### Input/Case mix
- Demographic data
- Admission data
- Diagnoses
- Severity of illness
  - APACHE II/III
  - SAPS II
  - MPMo24II
  - LODS

#### Outcome
- ICU and hospital mortality
- Length of stay

**Future outcome measures:**
- Quality of Life
- Costs of treatment
- Complications

*Figure 3.1 The NICE database contains data to describe input/case mix and the outcome of ICU treatment.*
3.4 Minimal data set

In 1999 the minimal data set consists of 96 variables representing characteristics of the patient population (input/case mix) and the outcome of ICU treatment. The data set concerns data in the first 24 hours of admission and at ICU and hospital discharge. It includes demographic patient data (e.g. age), admission and discharge data (e.g. reanimation prior to ICU admission, ICU date of admission, survival status) and all variables necessary to calculate the prognostic scoring models APACHE II [11], APACHE III [12], SAPS II [13], MPM0/24II [14] en LODS [15]. For each variable of the minimal data set, its definition, technical format, domain and practical examples are described in a data dictionary [16]. Original publications about the prognostic models and the data dictionary of the ICNARC Case Mix Programme have been used to unambiguously define each variable as far as possible. Figure 3.2 presents an example of a description of the variable “cardiac pulmonary resuscitation (reanimation prior to IC admission)” in the data dictionary. This is a typical example of a careful definition trying to rule out any ambiguity of the variable.

<table>
<thead>
<tr>
<th>Cardiac Pulmonary Resuscitation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indication</strong> if the patient has had a CPR (cardiac massage) within 24 hours prior to ICU admission. Defibrillation and/or precordial thumps without cardiac massage are excluded.</td>
</tr>
<tr>
<td>CPR is scored “yes” only if CPR occurred prior to ICU admission, independently of the place where the patient has had the CPR. Do not score when the patient has had the CPR during ICU admission.</td>
</tr>
</tbody>
</table>

**Example / Comments**

Patient arrives with acute angina on the emergency room. Ten minutes later, presentation of ventricular fibrillation for which cardiac massage was necessary. The patient is transfer to the CCU. Next night, respiratory insufficiency $\rightarrow$ ICU CPR $\rightarrow$ yes

Patient admitted to the CCU. Suddenly atrial fibrillation with high frequency and hypotension. Precordial thumps (twice) result in sinus rhythm. ICU admission due to hypotension and respiratory failure. CPR $\rightarrow$ no

This attribute is

<table>
<thead>
<tr>
<th>used</th>
<th>not used</th>
</tr>
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</table>

- APACHE II
- APACHE III
- SAPS II
- LODS II
- MPM 0
- MPM 24

**Technical**

<table>
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<tr>
<th>Attribute name</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data type</td>
<td>[1 (yes) / 0 (no)]</td>
</tr>
<tr>
<td>Domain</td>
<td>1.0</td>
</tr>
</tbody>
</table>

Figure 3.2 Example from the data dictionary describing the definition and format of the variable “Cardiac Pulmonary Resuscitation”. 
Chapter 3

3.5 Privacy protection by encryption

Although patients and participating ICUs have to be identifiable for patient follow-up and for communication between the hospital and the data analyser, the privacy of both patients and ICUs is protected in NICE. Each hospital has chosen a unique hospital number which is only known to the secretary of NICE. All communication, e.g. sending a data set from a participating hospital to the data analyser or sending the results of analysed data from the data analyser to the hospital, goes through the secretary of NICE.

To enable the follow-up of patients admitted to different ICUs, identifying data such as the patient’s name and number are essential. To protect the privacy of patients, only the encrypted names and numbers of the patients are imported in the national database intensive care. Decryption of these data is only possible in the hospital. Neither the NICE foundation nor the data analyser is able to decrypt the patient’s name and number. Each participating hospital uses the same encryption-algorithm, each with an own password. Despite the encryption of the patient’s name and number the national database intensive care is a registration of personal data. Therefore the national database intensive care is entered at the Dutch Data Protection Authority, a legal authority which protects the privacy of individuals whose data is entered in registers. Moreover, each participating hospital has to mention the use of ICU patient data for scientific research in general public relation material. Patient names and numbers will be totally removed for those patients who make objection to the use of the data leading to their identification in the national database intensive care.

3.6 Data processing

In this section, the process to turn data of an ICU patient into information to improve the quality of ICU treatment is described. Information, such as the surveys in the standard reports, is only meaningful when the quality of data used for these reports is adequate. Adequate quality of data implies complete and correct data. We distinguish two kinds of incomplete data: not all variables of the minimal data set are recorded or not all cases (admissions) are recorded. The prognostic scoring models suppose that missing data correspond to the normal value of that variable, e.g. a missing body temperature is assumed to be 37.0 degrees Celsius. The consequences of “normal” imputation of missing variables can be serious especially when it is systematic, e.g. when mainly the variables of non-survivors are not recorded or when the non-survivors are not recorded at all because they only stay a short and hectic period on the ICU. In both cases the difference between observed and expected mortality can be seriously biased.

To optimise the quality of data several procedures have been set up. First of all, at least two intensivist per participating hospital have to follow the NICE training program to learn the definitions of the data set variables and to become aware of common pitfalls in collecting the minimal data set. This knowledge has to be disseminated in each participating hospital, according to the train-the-trainer principle. Furthermore, each participating ICU is advised to implement the domain and inter-variable constraints, described in the data dictionary, into their local information system so that entry errors, e.g. age is less than zero or discharge date lies before admission date, is detected directly. The computer application to encrypt patient names and numbers provided by NICE can also be used to check domains of data. To control the completeness of cases, each ICU is advised to use an external file from the hospital information system with all admissions to the ICU. This file must also be used to complete the minimal data set of each admission with hospital discharge date and status.
Before the 7th of each month, the participating ICUs have to deliver a data set of patients discharged from their ICU the month before and a data set with hospital discharge data of patients whose data have already been sent in a former month. As soon as the NICE data manager receives the data set, it is imported into the national database. A quality report with comments on the data set structure, the completeness and validity of the data set (as far as it can be judged) is sent back to each ICU through the secretary. Improved data, based on this quality report, can be sent the next month together with data of new discharges. Each quarter of a year the standard report, which is defined in co-operation with the participating ICUs, is provided to the ICUs. Each report contains tables in which characteristics of the ICU population and the outcome of treatment (mortality and length of stay) are compared to the pooled average. Figure 3.3 represents the above described data delivering and processing activities.
3.7 Summary and Future work for NICE

NICE is an initiative for and by the professional group of intensivists, supported by scientific societies, to enable quality assurance and quality improvement of Dutch ICUs. After a pilot phase of 2 years in which ICU data of six hospitals were collected, and after the specifications of the minimal data set were finalised, participation became open for each interested ICU in the Netherlands. Active recruitment consisted of sending brochures to each Dutch ICU including an invitation for a conference organised in December 1999. Several ICUs have already shown interest. Hopefully, the NICE database will achieve national coverage, allowing comparison of outcome of an individual ICU to the national average or to the average of all comparable ICUs.

At this moment the minimal data set rests on mortality and length of stay as primary outcome measures. Prognostic scoring systems such as APACHE II, SAPS II, MPM0/24 II and LODS are all used to estimate case mix adjusted mortality risks. Because these models were developed on large USA/European populations some years ago, evaluation of the discrimination and calibration of these models to the Dutch population is necessary (see chapter 4).

At the start of the NICE foundation, we hypothesised that these prognostic systems could gain in accuracy and flexibility when detailed and structured diagnostic information, i.e. the reason for admission, was added as explanatory variable. We therefore schedule extension of the minimal data set with reason for admission as soon as the diagnostic classification (see chapters 9 and 10) is implemented. A natural next step will be the facilitation of an episode registration i.e. the registration of the origin and course of all health problems existing during ICU treatment. When episode registration is implemented, the next step is to relate therapy, interventions and resources consumed to health problems and episodes.

The current minimal data set can be collected in a simple computer application, but when episodes and therapies have to be collected a more extensive application such as a Patient Data Management System (see chapter 6) seems to be essential.

Although NICE, at this stage, helps to assess the quality of intensive care, quality assurance is not realised yet. Projects to ascertain the cause of discrepancies between individual ICUs and the best performing ICU, and to re-evaluate the performance of these ICUs after implementation of improvements, are started up now. For example seeking for differences in treatment to explain the differences in length of stay and mortality of CABG patients. Only when these steps are implemented in the NICE organisation it will become a complete quality assurance system.
References
